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ABSTRACT

This booklet was written to help parents decide what to tell their child who has cancer. It recommends that parents tell their child the truth about his disease to prevent him from feeling guilty and to increase his cooperation with treatment. A gentle, open, and honest approach is suggested. Sections discuss who should tell the child and when the child should be told about his or her illness. It is noted that the amount of information and the way it is presented to the child will depend on his age and intellectual maturity. Guidelines are suggested for talking with children at different ages (birth to 2 years; 2- to 7-year-olds, 7- to 12-year-olds, 12-year-olds and older). Suggestions are made for keeping open communication between parent and child. Six questions that a child may ask are listed and guidelines are presented for each question to help prepare parents to answer them. A section on supporting the child with cancer lists 14 suggestions for reassuring the child during the period of cancer diagnosis and treatment. It is noted that many of the ideas presented can also be used in discussions with the child's siblings and friends. The toll-free number for the National Cancer Institute (NCI) Cancer Information Service is given and free NCI publications are listed. (NB)

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Talking With Your Child About Cancer

CG 019331

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Being told that your child has cancer is perhaps the hardest news you have ever had to face. As a parent, you have the task of deciding what to tell your child. This booklet was written to help you decide on the best way.

The first question many parents ask is, "Should I tell my child about the cancer at all?" Although the trend in the past was to shield a child from the diagnosis, studies have shown that most children are aware that they have a serious illness despite attempts of parents and health care workers to protect them. Most likely, your child already suspects that something is wrong because he may not feel well, is seeing the doctor more often, and has already had some uncomfortable and frightening tests.* He may also sense the anxiety and fears of his close friends and family. If no one tells him about his illness, the child with cancer may depend on his imagination and fears to explain what is wrong. A child with cancer often believes that his illness is a punishment for something he has done wrong, and he may feel unnecessary anxiety and guilt. So now, medical professionals generally agree that telling a child the truth about his disease prevents him from feeling guilty and increases his cooperation with treatment. The questions that many parents focus on are, "Who should tell?" "When should my child be told?" and, "What should my child be told?"

*For simplicity, we are using the general term "he" to refer to children of both sexes.

J.P., age 8½

Who should tell?

The answer to this question is a personal one, and depends on the relationship you have with your child. Telling your child he has cancer is difficult. Who tells the child is up to you, and depends on your own feelings and attitudes. You may want to tell the child yourself, or you may, instead, want the doctor to explain the illness. Either way, you or someone your child is close to should be with him for support, encouragement, and love.

If you choose to tell your child, talking to others might help you decide what to say. Health professionals like your child's doctor, nurse, or social worker can offer valuable suggestions. Talking with parents of other children with cancer and members of support groups like the National Candlelighters Foundation* may also help. Thinking about what you want to say, discussing it with your child's doctor or nurse, and rehearsing it in front of the mirror are all ways to help you feel more at ease.

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*To find the Candlelighters chapter nearest you, contact The Candlelighters Childhood Cancer Foundation, Suite 1011, 2025 Eye Street, N.W., Washington, D.C. 20006, or call (202) 659-5136.

When should my child be told?
Because you are the best judge of your child's personality and moods, you are probably the best person to decide when your child should be told about his illness. Although there is no such thing as the perfect moment to tell a child he has cancer, a time and place which are quiet and have as few distractions as possible contribute to a calm, supportive atmosphere. It is probably best not to wait days or weeks after diagnosis to tell the child; waiting long periods gives the child more time to use his imagination and develop fears that may be hard to get rid of later on.

Before your child is told he has cancer, it is best that you understand the type of cancer and recommended treatment plan. This way, you can help your child by anticipating his questions and giving him accurate information.

What should my child be told?
The amount of information and the way it is presented to the child depend on his age and intellectual maturity. As a rule, a gentle, open, and honest approach is best for all children. The following information may help you determine what your child should be told. Please keep in mind that these are only general guidelines, and that your child may be described in more than one category or in none of them.

Birth to 2-Year-Olds
Children up to 2 years old are not yet able to understand an illness like cancer; they are more concerned with immediate events and separation from their parents. Children older than a year are concerned with how things feel and their ability to control their environment. Very young children are most worried about medical tests and pro-

cedures, and many try to control the situation by crying, running away, or squirming.

After 18 months, a child begins to use thought in order to figure out what is happening around him. A child at this age should never be told that he is not going to the hospital when he is, or that a procedure does not hurt when, in fact, it does. A more honest approach is better. Telling the child that needle sticks will hurt for a minute and that it is okay to cry lets him know that you acknowledge and accept his feelings.

"I hate shots because they hurt. I hate the needle sticks."
—David, age 12

Giving him honest expectations also promotes continuing trust in you. A child with cancer should still be allowed to exert some control if it does not interfere with his therapy or jeopardize his health. If a medicine is to be taken by mouth, for example, the child might be given the choice of having it mixed in apple juice, grape juice, or applesauce.

2- to 7-Year Olds

Children aged 2 to 7 are better able to understand illness. They typically understand events from one point of view—their own—and believe that the world revolves around them. They tend to classify events in terms of one feature, so their concept of illness is usually tied to a specific event, like staying in bed or eating chicken soup. Children at this age often think their illness

is caused by a specific action, and that recovery will come automatically or by following a set of rules.

A child this age needs to be reassured that nothing he did or did not do caused his illness, and that neither the illness nor its treatment are punishment for any wrongdoing. He also needs to have medical procedures explained honestly and realistically, and should be reminded that they are not meant as punishment.

Simple explanations about his illness are also important. Stories that relate the concept of cancer to ideas the child is familiar with are helpful in explaining the diagnosis; these comparisons may be tailored to the child's specific cancer type. The 2- to 7-year-old, for example, has some concept of good and bad and may understand his disease in terms of a battle between "good guy cells" and "bad guy cells;" taking his medicine will help the good guys become stronger so they can beat the bad guys.

Steph, age 8

Lori, age 11

7- to 12-Year Olds

Children aged 7 to 12 are still limited by their own experiences, but are able to understand relationships between several events. Thus, they are able to define illness as a combination of symptoms. They are less likely to believe that their illness is caused by something they did wrong. Children at this age are able to understand that recovery is the result of taking medicines and doing what the doctor says, and are able to cooperate with therapy.

An explanation of cancer to a child this age can be more detailed than for a younger child, but should still include situations he is familiar with. Comparisons are also useful in explaining cancer to children in this age group. You might say, for example, that there are different kinds of cells in the body, and these cells have different jobs to perform. Like people, these cells must work together to get their jobs done. Cancer cells can be explained as "trouble-makers" that disrupt the work of the good cells. Treatment helps to get rid of the "trouble-makers" so the other cells can work together once again.

12 Years and Older

Many children older than 12 years of age are able to understand complex relationships between events. Their explanations are no longer limited by their own experiences; now they are able to think about situations they have no prior experience with. Children in this age group not only define illness in terms of specific symptoms and limitations of everyday activities, but are also able to understand the reasons for their symptoms. They are able to understand that these symptoms result from the disturbance of the body's normal functions

by the cancer cells. Thus, you can explain cancer as a disease in which a few cells in the body go "haywire." These "haywire" cells grow more quickly than normal cells, invade other parts of the body, and disrupt the way the body normally functions. The goal of therapy is to destroy the "haywire" cells so that the body can function normally again.

Keeping Lines of Communication Open

Communicating with your child about cancer is a process that will continue throughout the different phases of treatment and followup care. As your child goes through these phases, he will continue to grow intellectually and to ask more complex questions. Setting up patterns of open communication early in his illness will support your child now, and will strengthen your relationship for years to come.

At times, you may feel strong emotions in the presence of your child. While parents do not want to burden their children with their own feelings of fear, anger, or sadness, children are aware of how their parents feel. In fact, children may hide their own feelings to protect their parents. You may want to discuss your feelings with your child if you think they interfere with your relationship. Telling your child why you are sad reassures him that you are not angry with him.

Throughout therapy it is important to remember that you, your child, and the medical care team are partners in the treatment process. You must all work together to treat your child's cancer. Your child is more likely to cooperate with treatment if he is informed about his therapy and allowed to make simple decisions

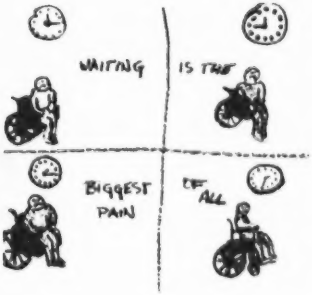
Melissa, age 7

which do not jeopardize his health. Sharing information about his disease and treatment is important because it increases his acceptance of treatment, helps him maintain a sense of self-control, and solicits his cooperation.

The medical care team may also help by asking your child to sign a pediatric assent form which is a simple explanation of treatment. By signing this form, the child states that he understands his treatment, agrees to cooperate, and feels free to ask questions.

Questions Your Child May Ask

Children are naturally curious and may have many questions about their illness and treatment. Because your child knows and trusts you, he will expect you to answer most of his questions. When your child will ask you questions is very individual; some children have questions right away, others will ask later on. The following guidelines may help prepare you for some of the questions your child is likely to ask.



Robby, age 15

"Why me?"

A child, like an adult, wonders why he developed cancer, and may feel that it was the result of something he did. A child with cancer should be told honestly that no one —not even the experts—know why he developed cancer, and that it was not due to anything he did, nor did he "catch" it from someone else.

"Will I get well?"

Frequently, children are aware of family members or friends who have died from cancer. As a result, many children are afraid to ask if they will get well because they fear the answer they will receive. A child with cancer should be told that he has a serious disease and will receive

"I got more used to it as time went on."
—Staci, age 16

treatments that will help him get rid of the cancer. He should also be told that his doctors, nurses, and family are trying their best to make him well. A response like this gives the child an honest, hopeful answer to his question, and makes him feel secure because he knows that many people will be involved in his care.

"What will happen to me?"
Children who have recently been diagnosed with cancer are exposed to many new and frightening things. While at the doctor's office, clinic, or hospital, they may have seen other children with cancer who are not feeling well, are bald, or have had amputations. Because he is too afraid to ask questions, the child may develop unrealistic fears about what will happen to him. For this reason, the child should be told in advance about his treatment, possible side effects, and what will be done about them should they occur. The child should also know that many types of cancer exist, and what happens to one child will not necessarily happen to him.

The child should also be told his treatment schedule and be informed of any changes. Having the child keep a calendar showing the days he is scheduled to visit the doctor, receive therapy, or have tests helps him prepare for these visits in advance.

"Why must I take medicines when I am feeling well?"

Children often associate taking medicines with feeling sick, and may be confused about why they need to take medicines when they are feeling well. Answers to these questions may relate back to the original explanation of cancer the child was given. For example, a child could be told that even though he is feeling well and has no signs of disease, the "bad guy cells" may be hiding. Therapy must be continued for a while longer to help keep the bad guys from coming back.

"I like to sleep when I get my chemotherapy because I don't feel like I want to do anything."—Amal, age 12

"What should I tell the kids at school?"

Children with cancer are concerned about how their friends and schoolmates will react, especially when they have been absent from school for a period of time, or return with obvious physical changes like weight gain or loss, or hair loss. The child should be encouraged to keep in touch with close friends and classmates, to talk honestly about his disease and the kind of treatment he needs, and to discuss what happens to him when he is away from school.

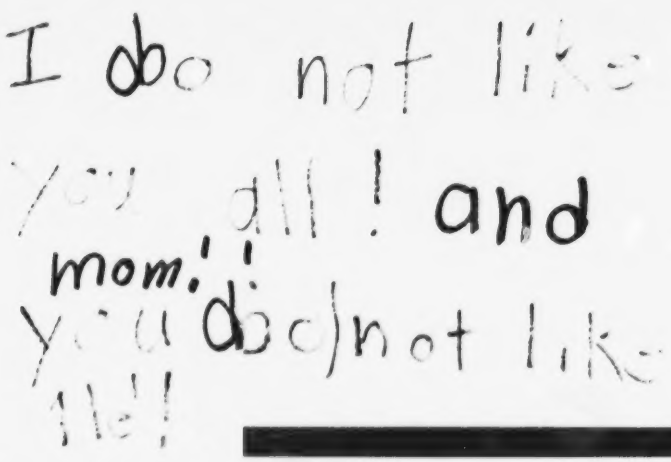
Even so, the child should be prepared for the fact that not all people, including some adults, know as much about his cancer as he does. These people may act differently toward him, and tell him things which may contradict what his parents or doctor may have said. Conversations like

these may cause the child to have doubts and fears despite all that you have told him. Your child should be encouraged to talk with you about these conversations, so that you can correct any misconceptions he may have. This is also a time for character building in your child, as he must learn several important lessons. First, having cancer does not make him a different person than he was before. Second, some people, no matter what they are told, may act differently because they do not know much about cancer and are not willing to learn. Third, those people who are truly his friends will remain his friends despite what others say.

"When something bad is going to happen, I don't think about the bad, I think about the good."—Jehanne, age 18

"Will I be able to do the things I did before I got cancer?"

The answer to this question is an individual one, and depends on the child's type of cancer and treatment. Most likely, your child will need some restrictions at different times during therapy. When the doctors or nurses tell you that restrictions are necessary, the child should be told why and how long they will be needed. Efforts should be made to substitute one kind of activity with another during this time. For example, if a child has been asked not to ride a bicycle because his platelet count is low, inviting his friends over to draw or paint may be an alternative.



Anonymous

Supporting Your Child

Like you, your child will have periods of uncertainty, anxiety, and fear. Unlike you, your child may not be able to talk about his fears, and may express such fears in subtle, nonverbal ways. As parents, you know how your child usually behaves, so you will most likely be the first one to detect nonverbal messages. Play is a way for a child to express fears and anxieties and should be encouraged. Drawing pictures, playing with puppets and dolls, and playing with medical supplies are ways your child may tell you that he does not understand what is happening, or that he needs more reassurance and love.

Some children find it hard to express their feelings. These children may have frequent nightmares, eating disturbances or behavior problems, or show a decline in school performance. Some children will also resume behaviors like bedwetting or thumb-sucking which they had previously outgrown. These should be discussed with the child's doctor, nurse, social worker, or school counselor.

It is important to remember that through the years, you as a parent have already developed a "sixth sense" about your

child. You do not need to look for problems in the way your child behaves. If problems exist they will be obvious to you. You must also remember that your child's physician, nurse, social worker, teachers, and school counselor have had experience with situations like yours, and may be able to help.

Remember also that your child has the same emotional needs as any other growing child. These are suggestions for reassuring your child during the period of cancer diagnosis and treatment:

1. Remind your child that the cancer is not caused by anything he did wrong, and that neither the disease nor the treatment are meant as punishment.
2. Be honest and realistic in your explanations of procedures and treatments. Let your child know about any changes in treatment.
3. Nobody—even your child—expects you to know everything. Don't be afraid to say "I don't know."
4. Don't be afraid to ask your child questions. Asking him what he is thinking will not make him have new fears; it will give him the opportunity to express the fears he already has.
5. Acknowledge your child's feelings. Telling your child that it is okay to feel sad and cry gives him an outlet for his emotions.
6. Set limits. During this period, your child may challenge the limits you've set for him. Although a natural tendency is to let children "bend the rules," leniency may actually make him more anxious and imagine that things are worse than they actually are.
7. Let your child exert some control as long as it does not jeopardize his health or interfere with his treatment. Giving the child

choices and scheduling treatment around school and social activities gives him the chance to maintain control and grow in spite of necessary restrictions.

8. Encourage acceptable methods of reducing anxiety. Drawing, playing with medical supplies, puppet shows, and role-playing are ways for the child to express his feelings.

9. Encourage your child to talk openly about his feelings. Frequent family discussions are a good way to reduce anxiety and help all family members cope with this illness together.

10. Recognize that children, like adults, have good days and bad days.

11. Remember that the medical care team is available to you and your family for questions and support.

12. Children, especially those under age 5, are concerned about separation from their parents. Reassure them that even though you have to leave, you love them and will return as soon as you can.

13. Encourage your child to keep in touch with friends, family members, and schoolmates while absent from school. Also encourage him to do his homework and to go back to school as soon as possible. This tells the child that despite his illness, he is still a normal kid with outside friends, interests, and responsibilities.

14. Despite all that is going on, your child is the same wonderful person he always was. Take some time each day to love and enjoy each other as you always have.

Talking with a child about cancer is not an easy task. We hope this information has given you some helpful suggestions. Many of the ideas presented here can also be applied to discussions with the child's siblings and friends.

As you and your family learn to cope with cancer you will undoubtedly have many questions. The National Cancer Institute sponsors a toll-free Cancer Information Service open 7 days a week to help you. By dialing 1-800-4-CANCER (1-800-422-6237)*, you will be connected to a Cancer Information Service office, where a trained staff member can answer your questions and listen to your concerns. Other NCI publications that may help you and your family include:

Young People with Cancer: A Handbook for Parents

When Someone in Your Family Has Cancer

Taking Time: Support for People with Cancer and the People Who Care About Them

Help Yourself: Tips for Teenagers with Cancer

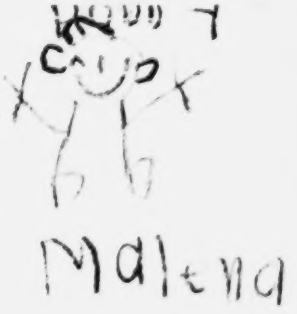
Hospital Days—Treatment Ways: A Hematology-Oncology Coloring Book

Diet and Nutrition: A Resource for Parents of Children with Cancer

These publications are free of charge and may be obtained by calling your Cancer Information Service, or by writing to:

National Cancer Institute
Building 31, Room 10A18
Bethesda, Maryland 20892

"My family is happy. I miss them when I am in the hospital."
—Malena, age 7



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